

From: "Skirboll, Lana (OD)" <SkirbolL@od1tm1.od.nih.gov>
To: "Harold Varmus" <varmus@nih.gov>
Cc: "Beaven, Vida (OD)" <BEAVENV@od1tm1.od.nih.gov>
Subject: stem cells ad nauseum
Date: Tue, 10 Nov 1998 19:16:06 -0500
MIME-Version: 1.0

First, I wanted to let you know that we had a conversation with Gearhart and he, too, was using the mouse ES cell definition of totipotency. He saw the problem with using it re the classic definition of totipotency. In fact, the Human Embryo Panel report defines totipotency as:

"having unlimited capability. The totipotent cells of the very early embryo have the capacity to differentiate into extraembryonic membranes and tissues, the embryo and all post-embryonic tissues and organs."

Clearly, these stem cells do not fit this definition.

He is willing to work with us to clear up the misunderstanding.

The briefing downtown was relatively uneventful - except it seems clear that because of John Gearharts work, they are going to take up the issue of fetal tissue research. Oy! I gently asked why they needed to go there, since this research is not banned. They said they would have to.

Bettilou said that Spector and Harkin were very excited about the potential for this research and Bettilou reiterated that the Senator would ask you to expand upon your comment in the NY Times that you were "sorry you could not fund" this research. They asked me to address this issue too. You and I had not really talked about this, but I pointed out the lack the Federal oversight, reminded them that the Human Embryo Panel suggested that NIH develop Guidelines, and talked about the importance of Federal dollars in any basic research effort. I alluded to the possibility of patents and licenses and then reminded them that most of the animal research that predicated this finding was Federally funded and that now the public might not be able to reap all the benefits from their previous investments. We will need to talk about how much of this you may or may not want to put into your written testimony.

You will be the first witness and are expected to give an overview of the science and related policy issues. They indicated that they hoped that we would have a reading from the Departmental lawyers prior to the hearing. (I had already told Bob that he would have to do this pronto. I will have the revised memo to you on Thursday.) The second panel will be Gearhart and Thomson. And the third panel will be ethicists for an against embryo and fetal tissue research!

We should try to touch base this week, prior to your departure, so we can at least take a stab at drafting testimony while you are gone. I guess you will be

deep into hot chilies when the alleged next, more dramatic, story comes out next. I have heard from several people that something real hot is about to explode on the scene, but I have no details.

Confidential!

They were not sure which members of the Committee might come to the hearing. I offered to brief other staff, if they needed me to do a repeat performance. Representatives from Spector, Harkin, Mack, and Inoyue were there today (I think I got them all).

Gee, thanks for reading from the Biocentury article while Francis was sitting there! By the way, I never spoke to either of the two reporters who wrote that article. Anne is calling to read them the riot act and find out what happened! I suspect they took somebody's cryptic notes from a background, off the record, discussion with me and turned it into a "Lana said" complete with the reporter's short hand version of things like "grantees can side-step the ban" and "NIH will issue a ruling." Ah well.

Lana